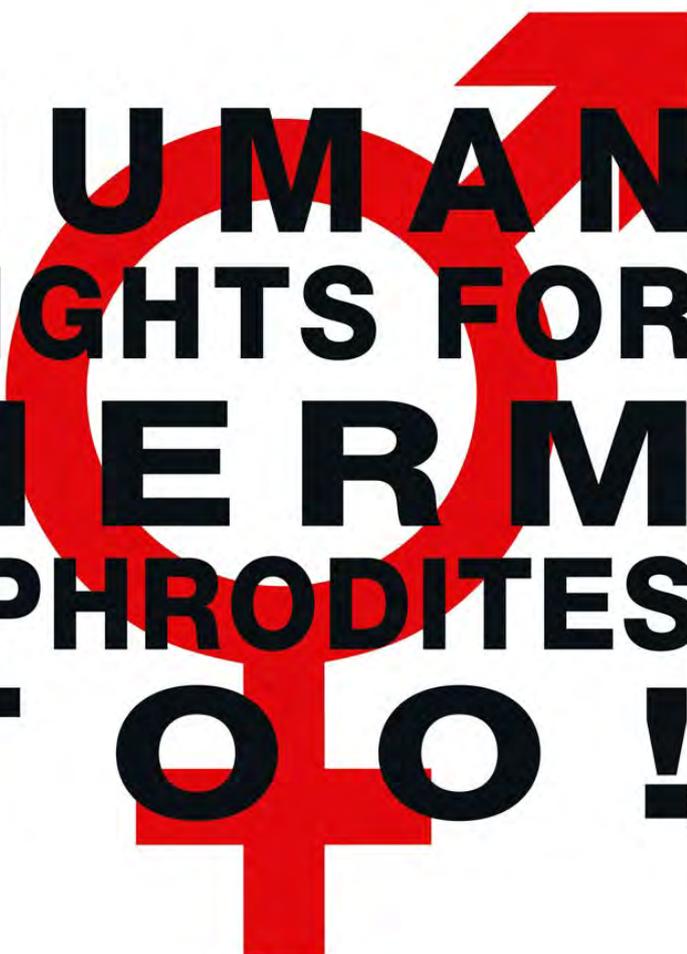


Intersex Genital Mutilation Human Rights Violations Of Children With Variations Of Reproductive Anatomy



**HUMAN
RIGHTS FOR
HERM
APHRODITES
TOO !**

NGO Report (for LOIPR)
to the 6th to 7th Report of Bulgaria on the
Convention on the Rights of the Child (CRC)

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Executive Summary

All typical forms of Intersex Genital Mutilation are still practised in Bulgaria, facilitated and paid for by the State party via the public health system. Parents and children are misinformed, kept in the dark, sworn to secrecy, kept isolated and **denied appropriate support.** Despite **repeated calls by intersex persons, NGOs and human rights agencies** to protect intersex children, **Bulgaria fails to act.**

Bulgaria is thus in breach of its **obligations** under CRC to **(a)** take effective legislative, administrative, judicial or other measures to **prevent harmful practices on intersex children** causing severe mental and physical pain and suffering of the persons concerned, and **(b)** **ensure access to redress and justice**, including fair and adequate **compensation** and as full as possible **rehabilitation** for victims, as stipulated in **CRC art. 24 para. 3** in conjunction with the **CRC-CEDAW Joint general comment No. 18/31** “on harmful practices”.

This Committee has consistently recognised IGM practices to constitute a harmful practice under the Convention in Concluding Observations.

In total, UN treaty bodies **CRC, CEDAW, CAT, CCPR** and **CRPD** have so far issued **50 Concluding Observations** recognising **IGM** as a **serious violation of non-derogable human rights**, typically obliging State parties to **enact legislation** to **(a)** end the practice and **(b)** ensure redress and compensation, plus **(c)** access to free counselling. Also, the UN Special Rapporteurs on Torture (**SRT**) and on Health (**SRH**), the UN High Commissioner for Human Rights (**UNHCHR**), the World Health Organisation (**WHO**), the Inter-American Commission on Human Rights (**IACHR**), the African Commission on Human and Peoples’ Rights (**ACHPR**) and the Council of Europe (**COE**) recognise **IGM** as a **serious violation of non-derogable human rights.**

Intersex people are born with **Variations of Reproductive Anatomy**, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. While intersex people may face several problems, in the “developed world” the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations.

IGM practices include **non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical procedures** that would not be considered for “normal” children, without evidence of benefit for the children concerned. **Typical forms of IGM** include “masculinising” and “feminising”, “corrective” genital surgery, sterilising procedures, imposition of hormones, forced genital exams, vaginal dilations, medical display, involuntary human experimentation and denial of needed health care.

IGM practices cause known **lifelong severe physical and mental pain and suffering**, including loss or impairment of sexual sensation, painful scarring, painful intercourse, incontinence, urethral strictures, impairment or loss of reproductive capabilities, lifelong dependency of artificial hormones, significantly elevated rates of self-harming behaviour and suicidal tendencies, lifelong mental suffering and trauma, increased sexual anxieties, and less sexual activity.

For more than **25 years**, intersex people have denounced **IGM** as **harmful** and **traumatising**, as western **genital mutilation**, as **child sexual abuse** and **torture**, and called for **remedies.**

This **NGO Report** has been compiled by **StopIGM.org / Zwischengeschlecht.org**, an international intersex NGO. It contains **Suggested Questions** (see p. 14).

**NGO Report (for LOIPR)
to the 6th to 7th Report of Bulgaria
on the Convention on the Rights of the Child (CRC)**

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A. Introduction

1. Bulgaria: Intersex, IGM and Human Rights

IGM practices are known to cause **severe, lifelong physical and psychological pain and suffering**, and have been repeatedly **recognised by multiple UN treaty bodies**¹ including CRC as constituting a **harmful practice**, violence, and cruel, inhuman or degrading treatment.

Despite that the persistence of IGM practices in Bulgaria is a **matter of public record**, same as the **criticism and appeals by intersex persons, NGOs and human rights agencies**, to this day the Bulgarian Government fails to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to **“take effective legislative, administrative, judicial or other measures” to protect intersex children from harmful practices**.

This Thematic NGO Report demonstrates that the current and ongoing **harmful medical practices on intersex children in Bulgaria** – advocated, facilitated and perpetrated by the state funded **University Hospitals**, as well as **private contractual hospitals**, and **paid for by the State party** via the **public health system** financed by the compulsory **National Health Insurance Fund (NHIF)** for employees and self-employed persons, and for **children aged 0-18 directly by the State** – constitute a **serious breach** of Bulgaria’s obligations under the Convention.

2. About the Rapporteurs

This NGO report has been prepared by the international intersex NGO *StopIGM.org*:

- **StopIGM.org / Zwischengeschlecht.org** is an international intersex human rights NGO based in Switzerland, working to end IGM practices and other human rights violations perpetrated on intersex people, according to its motto, *“Human Rights for Hermaphrodites, too!”*² According to its charter,³ StopIGM.org works to support persons concerned seeking redress and justice and regularly reports to relevant UN treaty bodies, often in collaboration with local intersex persons and organisations,⁴ substantially contributing to the so far 50 Treaty body Concluding Observations recognising IGM as a serious human rights violation.⁵

In 2017 StopIGM.org facilitated an **Open Letter** by persons concerned, partners, friends and allies with 101 signatories to **EU funded IGM clinics**, including the **Sofia University Hospital** and the **Varna University Hospital**.⁶

1 CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR (2016), “End violence and harmful medical practices on intersex children and adults, UN and regional experts urge”, <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

2 <https://Zwischengeschlecht.org/> English homepage: <https://StopIGM.org>

3 <https://zwischeneschlecht.org/post/Statuten>

4 <https://intersex.shadowreport.org>

5 <https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

6 The Open Letter to “I-DSD 2017” lists Bulgarian University Clinics involved in international IGM projects, see p. 1, https://stopigm.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

In addition, the Rapporteurs would like to acknowledge the work of pioneering Bulgarian intersex advocate and IGM survivor **Pol Naidenov**.⁷ And we would like to acknowledge some of the work of **Bilitis Resource Center Foundation**.^{8 9}

3. Methodology

This thematic NGO report is a localised update to the **2019 CRC Portugal NGO Report (for Session)**¹⁰ by the same Rapporteurs. Translations from Bulgarian texts are automatic translations revised by the Rapporteurs.

-
- 7 European Commission (2017), Video: Interview with Pol Naidenov, <https://audiovisual.ec.europa.eu/en/video/I-142954>
00:02:10: “Usually when parents agree to surgery they have no idea of the consequences of such surgery. Intersex people can live a long and happy life without any surgery.”
- 8 Monika Pisankaneva, Pol Naidenov (2020), Open Doors National Report: Bulgaria, https://bilitis.org/wp-content/uploads/2021/01/OpenDoors-National-Report-Bulgaria-FINAL_EN.pdf
p. 7: “(5) there is no legal ban on unnecessary surgery for intersex children which results in body mutilation procedures happening with the consent of the parents; intersex children raised in institutions are often subjects of unnecessary (exp[er]imental) surge[r]y, and last but not least, the parents of intersex children do not always receive present-day scientific information about the intersex conditions;”
p. 28: “Recommendations. The Bulgarian state should: [...] 2) Ban unnecessary corrective surgery for gender reassignment on intersex children, which is accomplished without the consent of the intersex individual.”
- 9 bilitis.org (2019), Council of Europe Commissioner for Human Rights, Dunja Mijatović, visited Bulgaria, <https://bilitis.org/en/council-of-europe-commissioner-for-human-rights-dunja-mijatovic-visited-bulgaria/>
“Furthermore, Liliya informed the Commissioner on the developments around a case of an intersex person who has been ‘normalized’ as an infant through series of damaging surgeries in a hospital in Sofia.”
- 10 <http://intersex.shadowreport.org/public/2019-CRC-Portugal-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

B. IGM in Bulgaria: State-sponsored and pervasive, Gov fails to act

1. Overview: IGM practices in Bulgaria: Pervasive and unchallenged

In **Bulgaria**, same as in the fellow **European Union member states** of *France* (CRC/C/FRA/CO/5, paras 47-48; CAT/C/FRA/CO/7, paras 34-35; CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f), *Denmark* (CRC/C/DNK/CO/5, paras 24+12; CAT/C/DNK/CO/6-7, paras 42-43), *Italy* (CRC/C/ITA/CO/5-6, para 23; CRPD/C/ITA/CO/1, paras 45-46), *Germany* (CAT/C/DEU/CO/5, para 20; CRPD/C/DEU/CO/1, paras 37-38; CEDAW/C/DEU/CO/7-8, paras 23-24), and in **many more State parties**,¹¹ there are

- **no legal or other protections** in place to **prevent all IGM practices** as stipulated in art. 24(3) and the CRC-CEDAW Joint General Comment No. 18/31,
- **no legal measures** in place to ensure **access to redress and justice** for adult IGM survivors,
- **no legal measures** in place to ensure the **accountability** of all IGM perpetrators and accessories,
- **no measures** in place to ensure **data collection and monitoring** of IGM practices.

Despite that the persistence of IGM practices in Bulgaria is a **matter of public record**, same as the **criticism and appeals** by **intersex persons, NGOs and human rights agencies** (see below, p. 12-13), to this day the Bulgarian Government fails to **recognise** the serious human rights violations and the severe pain and suffering caused by IGM practices, let alone to **“take effective legislative, administrative, judicial or other measures”** to **protect intersex children from harmful practices**.

2. Most Common IGM Forms advocated and perpetrated by Bulgaria

To this day, in **Bulgaria** all forms of IGM practices remain **widespread and ongoing**, persistently **advocated, prescribed and perpetrated** by the state funded **University Hospitals**, as well as **private contractual hospitals**, and **paid for by the State** via the **public health system** financed by the compulsory **National Health Insurance Fund (NHIF)** for employees and self-employed persons, and for **children aged 0-18 directly by the State**.

The best known hospitals practising IGM in Bulgaria are the **Sofia University Hospital** and the **Varna University Hospital “St. Marina”**, which are also involved in **international IGM networks**,¹² namely **“DSDnet”**,¹³ the IGM-related Main Thematic Group **“MTG7: Sex Development & Maturation”** of **“Endo-ERN”**¹⁴ and the **“I-DSD/I-CAH Registry”**.¹⁵

11 Currently we count **50 UN Treaty body Concluding Observations** explicitly condemning IGM practices as a **serious violation of non-derogable human rights**, see:

<https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

12 The Open Letter to “I-DSD 2017” lists Bulgarian University Clinics involved in international IGM projects, see p. 1, https://stopigm.org/public/Open_Letter_I-DSD_Copenhagen_2017.pdf

13 <http://www.dsdnet.eu/management-committee.html#Bulgaria>

14 <https://endo-ern.eu/reference-centre/mhat-sveta-marina/>

15 See for example participation in poster “Contemporary Surgical Approach in CAH 46XX – Results from the I-DSD/I-CAH Registries”, https://abstracts.eurospe.org/hrp/0092/eposters/hrp0092rfc10.1_eposter.pdf

However, the following sections **demonstrate** that besides the Sofia and Varna University Hospitals also various other **public University Hospitals** as well as **private clinics** practice IGM in Bulgaria.

Currently practiced forms of IGM in Bulgaria include:

a) IGM 3 – Sterilising Procedures:

**Castration / “Gonadectomy” / Hysterectomy /
Removal of “Discordant Reproductive Structures” / (Secondary) Sterilisation
Plus arbitrary imposition of hormones**¹⁶

The **Bulgarian Association of Urology (Българско Урологично Дружество)** endorses the **2019 Guidelines of the European Association of Urology (EAU)**,¹⁷ which (see p. 14) include the current **ESPU/EAU “Paediatric Urology” Guidelines**¹⁸ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU) which stress:¹⁹

“Individuals with DSD have an increased risk of developing cancers of the germ cell lineage, malignant germ cell tumours or germ cell cancer in comparison with to the general population.”

Further, regarding “*whether and when to pursue gonadal or genital surgery*”,²⁰ the Guidelines refer to the “*ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)*”,²¹ which advocates “gonadectomies”:

“Testes are either brought down in boys or removed if dysgenetic with tumour risk or in complete androgen insensitivity syndrome or 5 alpha reductase deficiency. Testicular prostheses can be inserted at puberty at the patient’s request.”

Also, the “**2016 Global Disorders of Sex Development Consensus Statement**”²² refers to the “*ESPU/SPU standpoint*”, advocates “*gonadectomy*” – even when admitting “*low*” cancer risk for CAIS (and despite explicitly acknowledging CRC/C/CHE/CO/2-4)²³:

16 For general information, see 2016 CEDAW NGO Report France, p. 47.

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

17 See p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

18 <https://uroweb.org/guideline/paediatric-urology/>

19 https://uroweb.org/guideline/paediatric-urology/#3_16_5

20 https://uroweb.org/guideline/paediatric-urology/#3_16_4

21 P. Mouriquand, A. Caldamone, P. Malone, J.D. Frank, P. Hoebcke, “The ESPU/SPU standpoint on the surgical management of Disorders of Sex Development (DSD)”, *Journal of Pediatric Urology* vol. 10, no. 1 (2014), p. 8-10, [http://www.jpurolog.com/article/S1477-5131\(13\)00313-6/pdf](http://www.jpurolog.com/article/S1477-5131(13)00313-6/pdf)

22 Lee et al., “Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care”, *Horm Res Paediatr* 2016;85:158–180, <https://www.karger.com/Article/Pdf/442975>

23 *Ibid.*, at 180 (fn 111)

Table 2. GCC risk: clinical management

	Male	Female	Unclear gender
Gonadal dysgenesis (45,X/46,XY and 46,XY)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Based on ultrasound and results of first biopsy – If CIS becomes GB → gonadectomy Low threshold for gonadectomy if ambiguous genitalia	Bilateral gonadectomy at diagnosis	Low threshold for gonadectomy if ambiguous genitalia If intact, gonadectomy depends on gender identity
Undervirilization (46,XY: partial AIS, complete AIS, testosterone synthesis disorders)	Undescended testes – Orchiopexy with biopsy – Self-examination – Annual ultrasound (post-puberty) Post-pubertal biopsy – Bilateral, CIS → gonadectomy/irradiation Repeat biopsy at 10 years of age – Consider gonadectomy to avoid gynecomastia or if on testosterone supplementation	Partial AIS and testosterone synthesis disorders – Prepubertal gonadectomy Complete AIS – Postpubertal gonadectomy or follow-up – GCC risk low, allow spontaneous puberty	Partial AIS and testosterone synthesis disorders – Bilateral biopsy – Low threshold for gonadectomy Intensive psychological counseling and follow-up
No data are available on the value of cryopreservation or safety if a precursor lesion for GCC is present.			

Source: Lee et al., in: Horm Res Paediatr 2016;85:158-180, at 174

Accordingly, a **2018 publication** out of the Maternity Clinic of the **Sofia University Hospital** states:²⁴

“In patients with 5-ARD who are raised female, management includes [...] early removal of testicles to prevent masculinisation before puberty, [...] and hormonal therapy at puberty for development of secondary sexual characteristics.”

And a **2018 publication** co-authored by doctors of the Department of Paediatrics at the **Medical University of Varna** associated with the I-DSD Registry regarding “the indications and timing of gonadectomy” within the Registry concludes:²⁵

“Data regarding gonadectomy were available in 520 (85%). [...] Gonadectomy was performed in 315 (61%) cases. Females had gonadectomy at a later median age of 14 yrs (0.3, 68) compared to median age of 5 yrs (0.1, 54) in males (P=0.047).”

24 Sirakov M., Andonova S., Savov A. (2018), “5- α -reductase type 2 deficiency”, Pediatric and Adolescent Reproductive Health. 2018; 14 (4): 72–8. doi: 10.24411/1816-2134-2018-14008. Received: 03.09.2018.

25 A Lucas-Herald, A Kyriakou, J Bryce, M Rodie, [Glasgow] C Acerini [Cambridge], W Arlt [Birmingham], A Balsamo, F Baronico [Bologna], S Bertelloni [Pisa], A Brooke [Exeter], H Claahsen van der Grinten [Nijmegen], M Cools, A Desloovere, [Ghent], F Darendeliler [Istanbul], JH Davies [Southampton], M Ellaithi Khartoum, S Fica [Bucharest], A Gawlik [Katowice], T Guran [Istanbul], S Hannema [Rotterdam, Leiden], O Hiort [Lübeck], PM Holterhus [Kiel], V Iotova [Varna], F Jennane [Casablanca], K Lachlan [Southampton], D Li [Jilin], L Lisa [Prague], I Mazen [Cairo], W Mladenov [Varna], K Mohnike [Magdeburg], L Nedelea [Bucarest], M Niedziela [Poznan], A Nordenstrom [Stockholm], S Poyrazoglu [Istanbul], R Rey [Buenos Aires], R Tadokoro-Cuccaro [Cambridge], N Weintrob [Tel Aviv], SF Ahmed [Glasgow] (2018), “Gonadectomy for Adults With DSD Conditions In The International Disorders of Sex Development Registry”, poster P1-P232 at the 57th Annual ESPE 2018, <https://abstracts.eurospe.org/hrp/0089/hrp0089p1-p232#authorAffiliates>

b) IGM 2 – “Feminising Procedures”: Clitoris Amputation/“Reduction”, “Vaginoplasty”, “Labiaplasty”, Dilatation²⁶

The **Bulgarian Association of Urology (Българско Урологично Дружество)** endorses the **2019 Guidelines of the European Association of Urology (EAU)**,²⁷ which (see p. 14) include the current **ESPU/EAU “Paediatric Urology” Guidelines**²⁸ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.16 “Disorders of sex development”**,²⁹ despite admitting that “Surgery that alters appearance is not urgent”³⁰ and that “adverse outcomes have led to recommendations to delay unnecessary [clitoral] surgery to an age when the patient can give informed consent”,³¹ the ESPU/EAU Guidelines nonetheless explicitly **refuse to postpone non-emergency surgery**, but in contrary **insist to continue with non-emergency genital surgery** (including partial clitoris amputation) on young children based on “*social and emotional conditions*” and **substituted decision-making by “parents and caregivers implicitly act[ing] in the best interest of their children**” and making “well-informed decisions [...] on their behalf”, and further **explicitly refusing “prohibition regulations”** of unnecessary early surgery,³² referring to the 2018 ESPU Open Letter to the Council of Europe (COE),³³ which further invokes **parents’ “social, and cultural considerations”** as justifications for early surgery (p. 2).

Accordingly, a **2018 publication** out of the Maternity of the **Sofia University Hospital** states:³⁴

“In patients with 5-ARD who are raised female, management includes surgical correction of the external genitalia (vaginal opening, with early separation of the vagina and urethra), [...] clitoral reduction [...]. Sometimes is needed to perform postsurgical dilatation of the vagina.”

And current online publication on “**Congenital Adrenal Hyperplasia**” by a doctor from the private **Medica Hospital in Ruse** (contractual hospital to the **National Health Insurance Fund (NHIF)** with a paediatric surgery department) prescribes:³⁵

“Surgical treatment

*Surgical treatment is **required** in some girls. This is usually done **around 1 year of age**. The type of surgery depends on the degree of masculinisation. The surgeon will **reduce the size of the clitoris**, preserving the blood vessels and nerve endings. In addition, **an opening to the vagina can be made** if necessary.*

26 For general information, see 2016 CEDAW NGO Report France, p. 48.

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

27 See p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

28 <https://uroweb.org/guideline/paediatric-urology/>

29 https://uroweb.org/guideline/paediatric-urology/#3_16

30 https://uroweb.org/guideline/paediatric-urology/#3_16_4

31 Ibid.

32 Ibid.

33 https://www.espu.org/images/documents/ESPU_Open_Letter_to_COE_2018-01-26.pdf

34 Sirakov M., Andonova S., Savov A. (2018), “5- α -reductase type 2 deficiency”, *Pediatric and Adolescent Reproductive Health*. 2018; 14 (4): 72–8. doi: 10.24411/1816-2134-2018-14008. Received: 03.09.2018.

Accepted: 10.12.2018, p. 5 / p. 76 in PDF, <https://cyberleninka.ru/article/n/5-reductase-type-2-deficiency/pdf>

35 Dr Mariana Moskova (2016), “Вродена надбъбречна хиперплазия при деца” (“Congenital adrenal hyperplasia in children”), 10.01.2016,

<https://www.credoweb.bg/publication/91868/vrodена-nadbabrechna-hiperplaziya-pri-detsa>

When puberty begins, these girls should be re-examined by a surgeon or gynaecologist. They will assess whether new surgery is needed.”

c) IGM 1 – “Masculinising Surgery”: Hypospadias “Repair”³⁶

The **Bulgarian Association of Urology (Българско Урологично Дружество)** endorses the **2019 Guidelines of the European Association of Urology (EAU)**,³⁷ which (see p. 14) include the current **ESPU/EAU “Paediatric Urology” Guidelines**³⁸ of the European Society for Paediatric Urology (ESPU) and the European Association of Urology (EAU). In **chapter 3.5 “Hypospadias”**,³⁹ the ESPU/EAU Guidelines’ **section 3.5.5.3 “Age at surgery”** nonetheless explicitly promotes, **“The age at surgery for primary hypospadias repair is usually 6-18 (24) months.”**⁴⁰ – despite admitting to the **“risk of complications”**⁴¹ and **“aesthetic[...]”** and **“cosmetic”** justifications.⁴²

Accordingly, a **2020 publication** out of the **University Hospital Stara Zagora** of the **Trakia University** about “redo surgery” due to complications notes:⁴³

“The surgical intervention aims to build a new urethra up to the tip of the penis, correcting any possible curvature of the penis (1-2). The correction is surgically, usually when the infant is between 6 and 24 months.”

“Hypospadias causes not only functional problems but also psychological problems for patients and their parents.”

*“We reviewed the boys with hypospadias repair of Snodgrass TIP urethroplasty, [which where] performed between **January 2013 - January 2020** in the Pediatric surgery department of University hospital –Stara Zagora. Cases of proximal hypospadias with severe chordae and those who had undergone previous urethroplasty were excluded. **Distal hypospadias in 12 boys aged 8 months to 12 years were included [...].**”*

*“Six patients have primary distal hypospadias who have been operated on by four pediatric surgeons **needed reoperations**, because of the failure of tabularized incised plate urethroplasty [...]. Two of them had **more than one operation in the same area.**”*

In a **2012 medical news article** the corresponding author of above publication elaborates:⁴⁴

“Says Assoc. Prof Dr Krassimira KALINOVA, Pediatric Surgery, University Hospital ‘Prof Dr St. Kirkovich’, Stara Zagora.”

36 For general information, see 2016 CEDAW NGO Report France, p. 48-49.

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

37 See p. 5, <https://www.scribd.com/document/411683225/EAU-2019-Full-Guidelines>

38 <https://uroweb.org/guideline/paediatric-urology/>

39 https://uroweb.org/guideline/paediatric-urology/#3_5

40 https://uroweb.org/guideline/paediatric-urology/#3_5_5_3

41 https://uroweb.org/guideline/paediatric-urology/#3_5_5_1

42 Ibid.

43 Kr. Kalinova, K. Georgiev (2020), “OUR EXPERIENCE IN DISTAL HIPOSPADIAS AND TIP URETHROPLASTY”, Trakia Journal of Sciences, No 4, pp 350-354,

[http://tru.uni-sz.bg/tsj/Volume%202018,%202020,%20Number4,%20Series%20Biomedical%20Sciences/10_K.Kalinova\(1\).pdf](http://tru.uni-sz.bg/tsj/Volume%202018,%202020,%20Number4,%20Series%20Biomedical%20Sciences/10_K.Kalinova(1).pdf)

44 Здравна поща (Health Mail) (2012), “Все по-чести при момченцата са аномалиите на половия член”

(“Penile abnormalities are becoming more common in boys”), 03.12.2012,

<http://www.zdravnaposhta.net/post/index.php/novini/za-deteto/141-vse-po-chesti-pri-momchentzata-sa-anomaliite-na-poloviya-chlen>

“Usually the boy does not complain about anything. The mother is the one who seeks medical help.”

“The treatment is only surgical. [...]

These deformities are surgically corrected before the child is two years old.

He can then urinate normally and have a full sexual life later.”

Above observation that the **children themselves have no issue with hypospadias** while the parents insist on surgery is also repeated in a **2014 online medical article** by a doctor from the **Plovdiv University Hospital**.⁴⁵

“Usually the boy does not complain about anything. The mother is the one who is anxious to seek medical help. [...] The treatment of hypospadias is only surgical.”

Further, also **private hospitals** perform “hypospadias repair”, for example the **Medical Complex Doverie** (contractual hospital to the **National Health Insurance Fund (NHIF)**) according to its homepage:⁴⁶

“Doverie Hospital already performs urological operations on children.”

“Also, with the help of prominent doctors, modern equipment is available to help deal with any of the types of diseases in children: [...] hypospadias, [...].”

“Hypospadias is another type of disease in young children. [...] In the specialised ward of Doverie Hospital, the disease can be easily diagnosed and the problem can be removed by surgery.”

“Our team of urologists [...] will take care of your child with great attention and concern.”

3. Bulgarian Doctors and Government consciously dismissing Intersex Human Rights

The persistence of IGM practices in Bulgaria is a **matter of public record**, same as the **criticism and appeals by intersex persons, NGOs and human rights agencies**.^{47 48 49 50 51}

45 Dr Iliya Bivolarski (2014), “Хипоспадия – лечение и симптоми” (“Hypospadias - treatment and symptoms”), <http://zdrave-bg.eu/%D1%85%D0%B8%D0%BF%D0%BE%D1%81%D0%BF%D0%B0%D0%B4%D0%B8%D1%8F/>

46 <https://www.mbal.doverie.bg/news/view/mbal-doverie-veche-izvyrshva-urologichni-operacii-i-na-deca>

47 Monika Pisankaneva, Pol Naidenov (2020), Open Doors National Report: Bulgaria, https://bilitis.org/wp-content/uploads/2021/01/OpenDoors-National-Report-Bulgaria-FINAL_EN.pdf
p. 7: “5) there is no legal ban on unnecessary surgery for intersex children which results in body mutilation procedures happening with the consent of the parents; intersex children raised in institutions are often subjects of unnecessary (experimental) surgery, and last but not least, the parents of intersex children do not always receive present-day scientific information about the intersex conditions;”

p. 28: “Recommendations. The Bulgarian state should: [...] 2) Ban unnecessary corrective surgery for gender reassignment on intersex children, which is accomplished without the consent of the intersex individual.”

48 European Commission (2017), Video: Interview with Pol Naidenov,

<https://audiovisual.ec.europa.eu/en/video/I-142954>

00:02:10: “Usually when parents agree to surgery they have no idea of the consequences of such surgery. Intersex people can live a long and happy life without any surgery.”

49 bilitis.org (2019), Council of Europe Commissioner for Human Rights, Dunja Mijatović, visited Bulgaria,

<https://bilitis.org/en/council-of-europe-commissioner-for-human-rights-dunja-mijatovic-visited-bulgaria/>

“Furthermore, Liliya informed the Commissioner on the developments around a case of an intersex person who has been ‘normalized’ as an infant through series of damaging surgeries in a hospital in Sofia.”

50 European Union Agency for Fundamental Rights FRA (2015), “FRA Focus: The fundamental rights situation of intersex people”, https://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-focus-04-intersex_en.pdf

However, **Bulgarian paediatric surgeons** nonetheless continue to **fail to consider any human rights concerns**.

And the **Bulgarian government fails to take practical and legislative measures** to protect intersex children from IGM practices.

4. Lack of Independent Data Collection and Monitoring

The **Bulgarian Government fails to collect and disclose disaggregated data** on intersex persons and IGM practices. With **no statistics available** on intersex births, let alone surgeries and costs, and **perpetrators, governments and health departments colluding to keep it that way as long as anyhow possible**, persons concerned as well as civil society **lack possibilities to effectively highlight and monitor** the ongoing mutilations. What's more, after realising how intersex genital surgeries are increasingly in the focus of public scrutiny and debate, perpetrators of IGM practices respond by suppressing complication rates, as well as refusing to talk to journalists "on record".

5. Obstacles to redress, fair and adequate compensation

Also in **Bulgaria** the **statutes of limitation** prohibit survivors of early childhood IGM practices to call a court, because persons concerned often **do not find out** about their medical history until much later in life, and **severe trauma** caused by IGM practices often prohibits them to act in time once they do.⁵² So far, in Bulgaria there was **no case** of a victim of IGM practices succeeding in going to court, despite survivors criticising the practice in public.

This situation is clearly not in line with Bulgaria's obligations under the Convention.

p. 6: "*Sex (re)assignment or sex-related surgery seems to be performed on intersex children, and young people, in at least 21 EU Member States (Austria, Belgium, **Bulgaria**, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, the Netherlands, Poland, Slovakia, Spain, Sweden and the United Kingdom). However, it is not known how frequently such operations are conducted.*"

51 Piet de Bruyn (2017), "Promoting the human rights of and eliminating discrimination against intersex people", Report to Committee on Equality and Non-Discrimination, CoE Doc. 14404, <https://pace.coe.int/pdf/0f9c0beef2be1c94882e907480ef9fb51f7a9acc3326667a8259ffe25682ae848428feba12/doc.%2014404.pdf>

p. 9: "22. A recent FRA study found that sex (re)assignment or sex-related surgery appeared to be performed on intersex children and young people in at least 21 European Union member States (Austria, Belgium, **Bulgaria**, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, the Netherlands, Poland, the Slovak Republic, Spain, Sweden and the United Kingdom). No indications could however be given as to the frequency of such surgery."

52 Globally, no survivor of early surgeries **ever** managed to have their case successfully heard in court. All relevant court cases resulting in damages or settlement (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

C. Suggested Questions for the LOIPR

The Rapporteurs respectfully suggest that in the LOIPR the Committee asks the Bulgarian Government the following questions with respect to the treatment of intersex children:

Harmful practices

Please inform the Committee about the measures taken to:

- **Prevent the unnecessary medical or surgical treatment of intersex children, provide families with intersex children with adequate counselling and support, and guarantee access to effective remedies for victims subjected to such treatment during childhood, including the statute of limitations.**

Please provide data, disaggregated, on:

- **The number of intersex children subjected to irreversible medical or surgical procedures.**

Annexe 1 – IGM Practices in Bulgaria as a Violation of CRC

1. The Treatment of Intersex Children in Bulgaria as Harmful Practice and Violence

a) Harmful Practice (art. 24(3) and JGC No. 18)⁵³

Article 24 para 3 CRC calls on states to abolish harmful “*traditional practices prejudicial to the health of children*”. While the initial point of reference for the term was the example of Female Genital Mutilation/Cutting (FGM/C), the term consciously wasn’t limited to FGM/C, but meant to include all forms of harmful, violent, and/or invasive traditional or customary practices.⁵⁴

This Committee has repeatedly considered IGM as a harmful practice, and the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices as applicable.⁵⁵

Also **CEDAW** has repeatedly considered IGM as a **harmful practice**, and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 on harmful practices as applicable.⁵⁶

Harmful practices (and inhuman treatment) have been identified by intersex advocates as the **most effective, well established and applicable human rights frameworks** to eliminate IGM practices and to end the impunity of the perpetrators.⁵⁷

The **CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices”** “*call[s] upon States parties to explicitly prohibit by law and adequately sanction or criminalize harmful practices, in accordance with the gravity of the offence and harm caused, provide for means of prevention, protection, recovery, reintegration and redress for victims and combat impunity for harmful practices*” (para 13).

Particularly, the Joint General Comment/Recommendation further underlines the need for a “**Holistic framework for addressing harmful practices**” (paras 31–36), including “**legislative, policy and other appropriate measures that must be taken to ensure full compliance with [state parties’] obligations under the Conventions to eliminate harmful practices**” (para 2), as well as

“*Data collection and monitoring*” (paras 37–39)

“*Legislation and its enforcement*” (paras 40–55), particularly:

“*adequate civil and/or administrative legislative provisions*” (para 55 (d))

53 For a more extensive version, see 2017 CRC Spain NGO Report, p. 12-13,

<https://intersex.shadowreport.org/public/2017-CRC-Spain-NGO-Brujula-Zwischengeschlecht-Intersex-IGM.pdf>

54 UNICEF (2007), Implementation Handbook for the Convention on the Rights of the Child, at 371

55 CRC/C/CHE/CO/2-4, paras 42-43; CRC/C/CHL/CO/4-5, paras 48-49; CRC/C/FRA/CO/5, paras 47-48; CRC/C/IRL/CO/3-4, paras 39-40; CRC/C/NPL/CO/3-5, paras 41-42; CRC/C/GBR/CO/5, paras 46-47; CRC/C/NZL/CO/5, paras 25+15; CRC/C/ZAF/CO/2, paras 39-40+23-24; CRC/C/DNK/CO/5, paras 24+12; CRC/C/ESP/CO/5-6, para 24; CRC/C/ARG/CO/5-6, para 26; CRC/C/ITA/CO/5-6, para 23; CRC/C/BEL/CO/5-6, paras 25(b)+26(e); CRC/C/MLT/CO/3-6, paras 28-29; CRC/C/AUS/CO/5-6, paras 25(b)+26(e); CRC/C/PRT/CO/5-6, paras 28(b); CRC/C/AUT/CO/5-6, para 27(a)-(b)

56 CEDAW/C/FRA/CO/7-8, paras 18e-f+19e-f; CEDAW/C/CHE/CO/4-5, paras 24-25, 38-39; CEDAW/C/NLD/CO/6, paras 21-22, 23-24; CEDAW/C/DEU/CO/7-8, paras 23-24; CEDAW/C/IRL/CO/6-7, paras 24-25; CEDAW/C/CHL/CO/7, paras 22-23, 12(d)-13(d), 14(d)-15(d); CEDAW/C/LUX/CO/6-7, paras 27b-c+28b-c; CEDAW/C/MEX/CO/9, para 21-22; CEDAW/C/NZL/CO/8, paras 23(c)-24(c); CEDAW/C/AUS/CO/8, paras 25(c)-26(c); CEDAW/C/LIE/CO/5, paras 35+36(c); CEDAW/C/NPL/CO/6, paras 18(c)-19(c)

57 Daniela Truffer, Markus Bauer / Zwischengeschlecht.org: “Ending the Impunity of the Perpetrators!” Input at “Ending Human Rights Violations Against Intersex Persons.” OHCHR Expert Meeting, Geneva 16–17.09.2015, online: https://StopIGM.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

*“provisions on **regular evaluation and monitoring**, including in relation to implementation, enforcement and follow-up”* (para 55 (n))

*“**equal access to justice**, including by **addressing legal and practical barriers to initiating legal proceedings**, such as **the limitation period**, and that **the perpetrators and those who aid or condone such practices are held accountable**”* (para 55 (o))

*“**equal access to legal remedies and appropriate reparations in practice**”* (para 55 (q)).

Last but not least, the Joint General Comment explicitly stipulates: *“Where **medical professionals or government employees or civil servants are involved or complicit in carrying out harmful practices**, their status and responsibility, including to report, should be seen as an **aggravating circumstance in the determination of criminal sanctions or administrative sanctions such as loss of a professional licence or termination of contract**, which should be preceded by the issuance of warnings. **Systematic training** for relevant professionals is considered to be an effective preventive measure in this regard.”* (para 50)

Conclusion, **IGM practices in Bulgaria** – as well as the **failure of the state party to enact effective legislative, administrative, social and educational measures** to eliminate them and to ensure effective access to remedies and redress for IGM survivors – clearly violate Article 24 CRC, as well as the CRC-CEDAW Joint General Comment No. 18/31 on harmful practices.

b) Violence against Children (art. 19 and GC No. 13)⁵⁸

Similarly, the Committee has also considered IGM practices as violence against children, and Art. 19 and the General Comment No. 13 also offer strong provisions to combat IGM practices.

2. Required Legislative Provisions to Ensure Protection from IGM Practices, Impunity of the Perpetrators (CRC art. 24(3) and JGC No. 18)

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices” (2014) underline state parties’ obligations to *“**explicitly prohibit by law and adequately sanction or criminalize harmful practices**”* (JGC 18/31, para 13), as well as to *“**adopt or amend legislation with a view to effectively addressing and eliminating harmful practices**”* (JGC 18/31, para 55), and specifically to ensure *“**that the perpetrators and those who aid or condone such practices are held accountable**”* (JGC 18/31, para 55 (o)).

Accordingly, with regards to IGM practices, and referring to Article 24 para 3 and the CRC-CEDAW Joint General Comment/Recommendation No. 18/31, CRC repeatedly recognised the obligation for State parties to *“**[e]nsure that the State party’s legislation prohibits all forms of harmful practices [including intersex genital mutilation]**”*,⁵⁹ as well as to *“**ensure that no-one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to children concerned**”*,⁶⁰ and to *“**[u]ndertake investigation of incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions in order to provide redress to the victims of such treatment, including adequate compensation**”*.⁶¹

58 For a more extensive version with sources, see 2016 CRC UK Thematic NGO Report, p. 57, https://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

59 CRC/C/ZAF/CO/2, 27 October 2016 paras 39–40

60 CRC/C/CHE/CO/2-4, 26 February 2015, para 43

61 CRC/C/DNK/CO5, 26 October 2017, para 24

3. Obstacles to Redress, Fair and Adequate Compensation, and Rehabilitation (CRC art. 24(3) and JGC No. 18)

Article 24 para. 3 of the Convention in conjunction with the CRC-CEDAW Joint General Comment/Recommendation No. 18/31 “on harmful practices” clearly stipulate the right of victims of IGM practices to “*equal access to legal remedies and appropriate reparations*” (JGC 18/31, para 55 (q)), and specifically to ensure that “*children subjected to harmful practices have equal access to justice, including by addressing legal and practical barriers to initiating legal proceedings, such as the limitation period*” (JGC 18/31, para 55 (o)).

However, also in **Bulgaria** the **statutes of limitation** prohibit survivors of early childhood IGM practices to call a court, because persons concerned often **do not find out** about their medical history until much later in life, and **severe trauma** caused by IGM practices often prohibits them to act in time even once they do.⁶² So far there was no case of a victim of IGM practices succeeding in going to an Bulgarian court.

62 Globally, no survivor of early surgeries **ever** managed to have their case successfully heard in court. All relevant court cases resulting in damages or settlement (3 in Germany, 1 in the USA) were either about surgery of adults, or initiated by foster parents.

Annexe 2 – Intersex, IGM and Non-Derogable Human Rights

1. Intersex = variations of reproductive anatomy

Intersex persons, in the vernacular also known as hermaphrodites, or medically as persons with “Disorders” or “Differences of Sex Development (DSD)”,⁶³ are people born with **variations of reproductive anatomy**, or “atypical” reproductive organs, including atypical genitals, atypical sex hormone producing organs, atypical response to sex hormones, atypical genetic make-up, atypical secondary sex markers. Many intersex forms are usually detected at **birth** or earlier during **prenatal testing**, others may only become apparent at **puberty** or **later in life**.

While intersex people may face several problems, in the “developed world” the most pressing are the ongoing **Intersex Genital Mutilations**, which present a distinct and unique issue constituting significant human rights violations, with **1 to 2 in 1000 newborns** at risk of being submitted to non-consensual “genital correction surgery”.

*For more information and references, see 2014 CRC Switzerland NGO Report, p. 7-12.*⁶⁴

2. IGM = Involuntary, unnecessary and harmful interventions

In “**developed countries**” with universal access to paediatric health care **1 to 2 in 1000 newborns** are at risk of being submitted to medical **IGM practices**, i.e. non-consensual, unnecessary, irreversible, cosmetic genital surgeries, and/or other harmful medical treatments that **would not be considered for “normal” children**, practiced without evidence of benefit for the children concerned, but justified by societal and cultural norms and beliefs, and often **directly financed by the state** via the public health system.⁶⁵

In **regions without universal access to paediatric health care**, there are reports of **infanticide**⁶⁶ of intersex children, of **abandonment**,⁶⁷ of **expulsion**,⁶⁸ of **massive bullying** preventing the

63 The currently still official medical terminology “Disorders of Sex Development” is strongly refused by persons concerned. See 2014 CRC NGO Report, p. 12 “Terminology”.

64 https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

65 For references and general information, see 2015 CAT NGO Report Austria, p. 30-35, <https://intersex.shadowreport.org/public/2015-CAT-Austria-VIMOE-Zwischengeschlecht-Intersex-IGM.pdf>

66 For Nepal, see CEDAW/C/NPL/Q/6, para 8(d). See also 2018 CEDAW Joint Intersex NGO Report, p. 13-14, <https://intersex.shadowreport.org/public/2018-CEDAW-Nepal-NGO-Intersex-IGM.pdf>

For example in South Africa, see 2016 CRC South Africa NGO Report, p. 12,

<https://intersex.shadowreport.org/public/2016-CRC-ZA-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

For South Africa, see also <https://mg.co.za/article/2018-01-24-00-intersex-babies-killed-at-birth-because-theyre-bad-omens>

For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

; for Uganda, see also 2015 CRC Briefing, slide 46,

https://intersex.shadowreport.org/public/Zwischengeschlecht_2015-CRC-Briefing_Intersex-IGM_web.pdf

For Kenya, see also <http://www.bbc.com/news/world-africa-39780214>

For Mexico, see 2018 CEDAW NGO Joint Statement,

<https://stopigm.org/post/CEDAW70-Mexico-Joint-Intersex-NGO-Statement-05-07-2018>

67 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

For example in China, see 2015 Hong Kong, China NGO Report, p. 15,

<https://intersex.shadowreport.org/public/2015-CAT-Hong-Kong-China-NGO-BBKCI-Intersex.pdf>

68 For example in Uganda, Kenya, Rwanda, see "Baseline Survey on intersex realities in East Africa – Specific focus on Uganda, Kenya, and Rwanda" by SIPD Uganda, relevant excerpts and source:

<https://stopigm.org/post/Africa-Intersex-Survey-Documents-Intersex-Genital-Mutilation-Infanticide-Abandonment-Expulsion-Uganda-Kenya-Rwanda>

persons concerned from attending school (recognised by CRC as amounting to a harmful practice),⁶⁹ and of **murder**.⁷⁰

Governing State bodies, public and private healthcare providers, national and international medical bodies and individual doctors have traditionally been **framing and “treating”** healthy intersex children as **suffering from a form of disability in the medical definition**, and in need to be **“cured” surgically**, often **with openly racist, eugenic and supremacist implications**.^{71 72 73 74}

Both in “developed” and “developing” countries, **harmful stereotypes and prejudice** framing intersex as **“inferior”, “deformed”, “disordered”, “degenerated” or a “bad omen”** remain widespread, and to this day inform the current harmful **western medical practice**, as well as other practices including **infanticide and child abandonment**.

Typical forms of medical IGM include “feminising” or “masculinising”, “corrective” genital surgery, sterilising procedures, imposition of hormones (including prenatal “therapy”), forced genital exams, vaginal dilations, medical display, human experimentation, selective (late term) abortions and denial of needed health care.

Medical IGM practices are known to cause **lifelong severe physical and mental pain and suffering**,⁷⁵ including loss or impairment of sexual sensation, poorer sexual function, painful scarring, painful intercourse, incontinence, problems with passing urine (e.g. due to urethral stenosis after surgery), increased sexual anxieties, problems with desire, less sexual activity, dissatisfaction with functional and aesthetic results, lifelong trauma and mental suffering, elevated rates of self-harming behaviour and suicidal tendencies comparable to those among women who have experienced physical or (child) sexual abuse, impairment or loss of reproductive capabilities, lifelong dependency on daily doses of artificial hormones.

UN Treaty bodies and other human rights experts have consistently recognised IGM practices as a serious violation of non-derogable human rights, namely as a harmful practice and inhuman treatment falling under the absolute prohibition of torture.⁷⁶ **UN Treaty bodies have so far issued 50 Concluding Observations condemning IGM practices accordingly.**⁷⁷

69 For example in Nepal (CRC/C/NPL/CO/3-5, paras 41–42), based on local testimonies, see

<https://stopigm.org/post/Denial-of-Needed-Health-Care-Intersex-in-Nepal-Pt-3>

70 For example in Kenya, see <https://76crimes.com/2015/12/23/intersex-in-kenya-held-captive-beaten-hacked-dead/>

71 2014 CRC NGO Report, p. 52, 69, 84, https://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

72 In the WHO “World Atlas of Birth Defects (2nd Edition)”, many intersex diagnoses are listed, including “*indeterminate sex*” and “*hypospadias*”:

<http://web.archive.org/web/20160305152127/http://prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf>

73 “The Racist Roots of Intersex Genital Mutilations”

<https://stopigm.org/post/Racist-Roots-of-Intersex-Genital-Mutilations-IGM>

74 For 500 years of “scientific” prejudice in a nutshell, see 2016 CEDAW France NGO Report, p. 7,

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

75 See “IGM Practices – Non-Consensual, Unnecessary Medical Interventions”, *ibid.*, p. 38–47

76 **CAT, CRC, CRPD, SPT, SRT, SRSG VAC, COE, ACHPR, IACHR** (2016), “End violence and harmful medical practices on intersex children and adults, UN and regional experts urge”,

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

77 <https://stopigm.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>

3. Intersex is NOT THE SAME as LGBT or Transgender

Unfortunately, there are also other, often interrelated **harmful misconceptions and stereotypes about intersex** still prevailing in public, notably if intersex is counterfactually described as being the same as or a subset of LGBT or SOGI, e.g. if intersex is misrepresented as a sexual orientation (like gay or lesbian), and/or as a gender identity, as a subset of transgender, as the same as transsexuality, or as a form of sexual orientation.

The underlying reasons for such harmful misrepresentations include **lack of awareness**, third party groups **instrumentalising intersex as a means to an end**^{78 79} for their own agenda, and State parties **trying to deflect** from criticism of involuntary intersex treatments.

Intersex persons and their organisations have spoken out clearly against instrumentalising or misrepresenting intersex issues,⁸⁰ maintaining that IGM practices present a **distinct and unique issue** constituting significant human rights violations, which are different from those faced by the LGBT community, and thus need to be **adequately addressed in a separate section as specific intersex issues**.

Also, **human rights experts** are increasingly warning of the **harmful conflation** of intersex and LGBT.^{81 82}

Regrettably, **these harmful misrepresentations seem to be on the rise also at the UN**, for example in recent **UN press releases** and **Summary records** misrepresenting IGM as “*sex alignment surgeries*” (i.e. voluntary procedures on transsexual or transgender persons), IGM survivors as “*transsexual children*”, and intersex NGOs as “*a group of lesbians, gays, bisexuals, transgender and intersex victims of discrimination*”,⁸³ and again IGM survivors as “*transgender children*”,⁸⁴ “*transsexual children who underwent difficult treatments and surgeries*”, and IGM as a form of “*discrimination against transgender and intersex children*”⁸⁵ and as “*sex assignment surgery*” while referring to “*access to gender reassignment-related treatments*”.⁸⁶

Particularly **State parties** are constantly **misrepresenting intersex and IGM as sexual orientation or gender identity issues** in an attempt to **deflect from criticism** of the serious human rights violations resulting from IGM practices, instead referring to e.g. “*gender reassignment surgery*” (i.e. voluntary procedures on transsexual or transgender persons) and “*gender assignment surgery for children*”,⁸⁷ “*a special provision on sexual orientation and*

78 CRC67 Denmark, <https://stopigm.org/post/CRC67-Intersex-children-used-as-cannon-fodder-LGBT-Denmark>

79 CEDAW66 Ukraine, <https://stopigm.org/post/Ukraine-Instrumentalising-Intersex-and-IGM-for-LGBT-and-Gender-Politics>

80 For references, see 2016 CEDAW France NGO Report, p. 45

<https://intersex.shadowreport.org/public/2016-CEDAW-France-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

81 For example ACHPR Commissioner Lawrence Murugu Mute, see

<https://stopigm.org/post/ACHPR-African-Commissioner-warns-Stop-conflating-intersex-and-LGBT>

82 2018 Report of the Kenya National Commission on Human Rights (KNCHR), p. 15,

https://www.knchr.org/Portals/0/GroupRightsReports/Equal%20In%20Dignity%20and%20Rights_Promoting%20The%20Rights%20Of%20Intersex%20Persons%20In%20Kenya.pdf?ver=2018-06-06-161118-323

83 CAT60 Argentina, <https://stopigm.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CATArgentina-UNCAT60>

84 CRC77 Spain, <https://stopigm.org/post/UN-Press-Release-mentions-genital-mutilation-of-intersex-children>

85 CRC76 Denmark, <https://stopigm.org/post/UN-Press-Release-calls-IGM-survivors-transsexual-children-CRC-Denmark-UNCRC67>

86 CAT/C/DNK/QPR/8, para 32

87 CRC73 New Zealand, <https://stopigm.org/post/NZ-to-be-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-the-Child>

gender identity”, “civil registry” and “sexual reassignment surgery”⁸⁸, transgender guidelines⁸⁹ or “Gender Identity”^{90 91} when asked about IGM by e.g. Treaty bodies.

What’s more, **LGBT organisations** (including “LGBTI” organisations without actual intersex representation or advocacy) are using the ubiquitous misrepresentation of intersex = LGBT to **misappropriate intersex funding**, thus **depriving actual intersex organisations** (which mostly have no significant funding, if any) of much needed **resources**⁹² and public **representation**.⁹³

4. IGM is NOT a “Discrimination” Issue

An interrelated diversionary tactic is the **increasing misrepresentation by State parties of IGM as “discrimination issue”** instead of a serious violation of non-derogable human rights, namely inhuman treatment and a harmful practice, often in combination with the **misrepresentation of intersex human rights defenders as “fringe elements”**, and their legitimate demands and criticism of such downgrading and trivialising of IGM as “*extreme views*”.

5. IGM is NOT a “Health” Issue

An interrelated, alarming new trend is the **increasing misrepresentation of IGM as “health-care issue”** instead of a serious violation of non-derogable human rights, and the **promotion of “self-regulation” of IGM by the current perpetrators**^{94 95 96 97} – instead of effective measures to finally end the practice (as repeatedly stipulated also by this Committee).

Even worse, **Health Ministries** construe UN Concluding observations falling short of explicitly recommending legislation to criminalise or adequately sanction IGM as an **excuse for “self-regulation” promoting state-sponsored IGM practices to continue with impunity**.^{98 99 100}

88 CCPR120 Switzerland,

<https://stopigm.org/post/Pinkwashing-of-Intersex-Genital-Mutilations-at-the-UN-CCPR120>

89 CAT56 Austria, <https://stopigm.org/post/Geneva-UN-Committee-against-Torture-questions-Austria-over-Intersex-Genital-Mutilations>

90 CAT60 Argentina, <https://stopigm.org/post/CAT60-Argentina-to-be-Questioned-on-Intersex-Genital-Mutilation-by-UN-Committee-against-Torture>

91 CRPD18 UK, <https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

92 For example in Scotland (UK), LGBT organisations have so far collected at least **£ 135,000.–** public intersex funding, while actual intersex organisations received ZERO public funding, see 2017 CRPD UK NGO Report, p. 14, <https://intersex.shadowreport.org/public/2017-CRPD-UK-NGO-Coalition-Intersex-IGM.pdf>

Typically, during the interactive dialogue with CRPD, the UK delegation nonetheless tried to sell this glaring misappropriation as “supporting intersex people”, but fortunately got called out on this by the Committee, see transcript (Session 2, 10:53h + 11:47h), <https://stopigm.org/post/UK-Questioned-over-Intersex-Genital-Mutilations-by-UN-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD>

93 See e.g. “Instrumentalizing intersex: ‘The fact that LGBTs in particular embrace intersex is due to an excess of projection’ - Georg Klauda (2002)”, <https://stopigm.org/post/Instrumentalizing-Intersex-Georg-Klauda-2002>

94 For example Amnesty (2017), see <https://stopigm.org/post/Amnesty-Report-fails-Intersex-Children-and-IGM-Survivors>

95 For example FRA (2015), see Presentation OHCHR Expert Meeting (2015), slide 8,

https://stopigm.org/public/S3_Zwischengeschlecht_UN-Expert-Meeting-2015_web.pdf

96 For example CEDAW Italy (2017), see <https://stopigm.org/post/Major-Setback-for-Intersex-Human-Rights-at-the-UN>

97 For example CEDAW Austria (2019): CEDAW/C/AUT/CO/9, paras 34(h), 35(h)

98 For example Ministry of Health Chile (2016), see

<https://stopigm.org/post/Circular-7-step-back-for-intersex-human-rights-in-Chile>

99 For example Ministry of Health France (2018), see 2020 CRC Intersex NGO Report (for LOIPR), p. 19,

<https://intersex.shadowreport.org/public/2020-CRC-France-LOIPR-NGO-Intersex-IGM.pdf>

100 For example Ministry of Health Austria (2019), see 2019 CRC Intersex NGO Report (for Session), p. 4-5,

<https://intersex.shadowreport.org/public/2019-CRC-Austria-NGO-Zwischengeschlecht-Intersex-IGM.pdf>

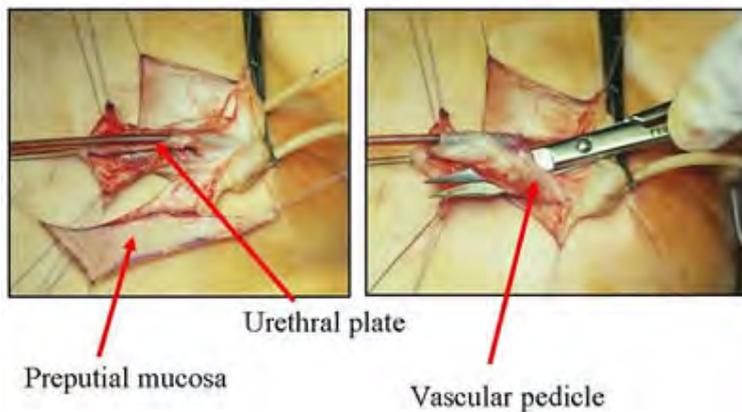
Annexe 3 – “IGM in Medical Textbooks: Current Practice”

IGM 1 – “Masculinising Surgery”: “Hypospadias Repair”

“Hypospadias,” i.e. when the urethral opening is not on the tip of the penis, but somewhere on the underside between the tip and the scrotum, is arguably the most prevalent diagnosis for cosmetic genital surgeries. Procedures include dissection of the penis to “relocate” the urinary meatus. Very high complication rates, as well as repeated “redo procedures” — “5.8 operations (mean) along their lives ... and still most of them are not satisfied with results!”

Nonetheless, clinicians recommend these surgeries without medical need explicitly “for psychological and aesthetic reasons.” Most hospitals advise early surgeries, usually “between 12 and 24 months of age.” While survivors criticise a.o. impairment or total loss of sexual sensation and painful scars, doctors still fail to provide evidence of benefit for the recipients of the surgeries.

Onlay island flap urethroplasty



Onlay / Duckett - results

- Elbakry (BJUI 88: 590-595, 2001): 42% complications
 - 5 breakdowns (7%)
 - 17 fistulae (23%)
 - Urethral strictures (9%)
 - Urethral diverticulae (4%)
- Asopa / Duckett tube
 - 3.7% (El-Kasaby J Urol 136: 643-644, 1986)
 - 69% (Parsons BJU 25: 186-188, 1984)
 - 15% (Duckett - 1986)



Hypospadias - Procedures for cripple hypospadias

- No standardized procedures
- Personal experience of the surgeon
- Importance of a uro-endocrine approach of complex cases to increase the healing abilities of the penile tissues



Official Diagnosis "Hypospadias Cripple"
= made a "cripple" by repeat cosmetic surgeries

Treatment of isolated fistulae

- Rectangular skin incision around the fistula orifice, often lateral
- Dissection and excision of the fistula tract
- Urethral suture
- Multilayer cover with well-vascularized tissue (tunica vaginalis, dartos, dorsal subcutaneous flap ...)
- Problem: coronal fistula +++: Prefer redo urethroplasty
- Suprapubic diversion ? Elbakry



Bad cosmetic result



infection

Hypospadias - Conclusions

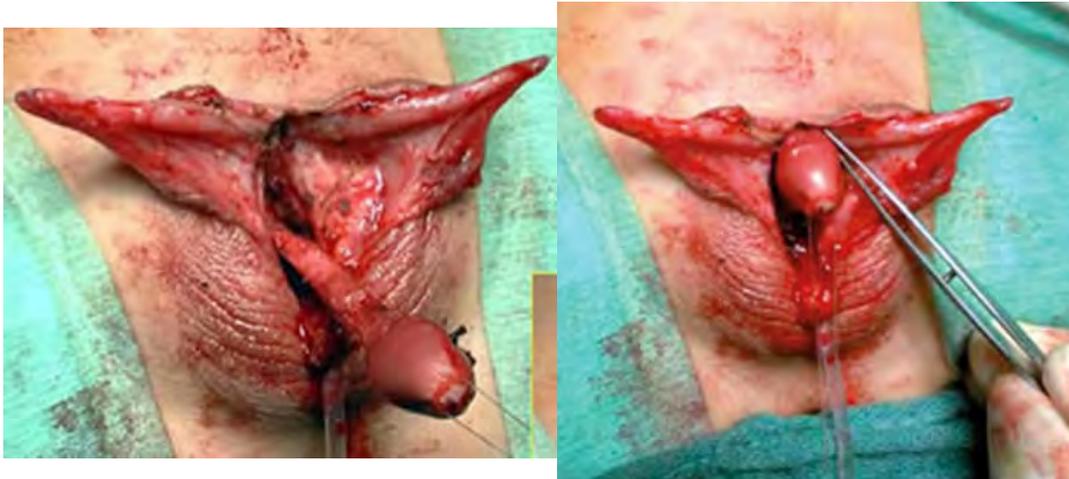
- Hypospadias surgery remains a surgical challenge
- Long-term results are poorly reported
- Essential joint uro-endocrine approach
- Psychological consequences poorly assessed
- Informing parents is crucial: 50% of all hypospadias will require further surgical attention during their life.
- Research: Essential role of the placenta / Penile growth factors / healing factors / blood supply ...

Source: Pierre Mouriquand: "Surgery of Hypospadias in 2006 - Techniques & outcomes"

IGM 2 – "Feminising Surgery": "Clitoral Reduction", "Vaginoplasty"

Partial amputation of clitoris, often in combination with surgically widening the vagina followed by painful dilation. "46,XX Congenital Adrenal Hyperplasia (CAH)" is arguably the second most prevalent diagnosis for cosmetic genital surgeries, and the most common for this type (further diagnoses include "46,XY Partial Androgen Insufficiency Syndrome (PAIS)" and "46,XY Leydig Cell Hypoplasia").

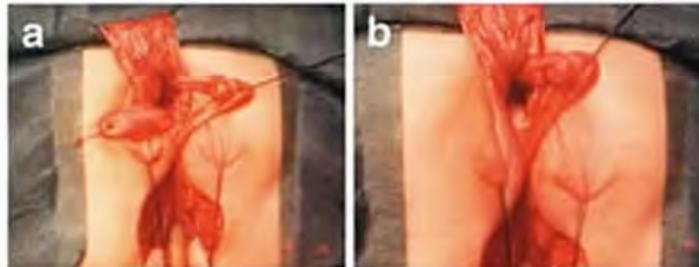
Despite numerous findings of impairment and loss of sexual sensation caused by these cosmetic surgeries, and lacking evidence for benefit for survivors, current guidelines nonetheless advise surgeries "*in the first 2 years of life*", most commonly "*between 6 and 12 months,*" and only 10.5% of surgeons recommend letting the persons concerned decide themselves later.



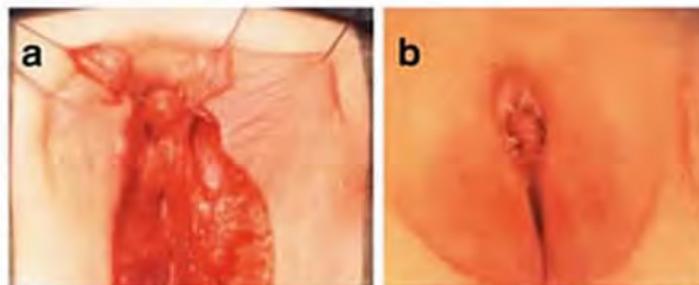
Source: Christian Radmayr: *Molekulare Grundlagen und Diagnostik des Intersex*, 2004



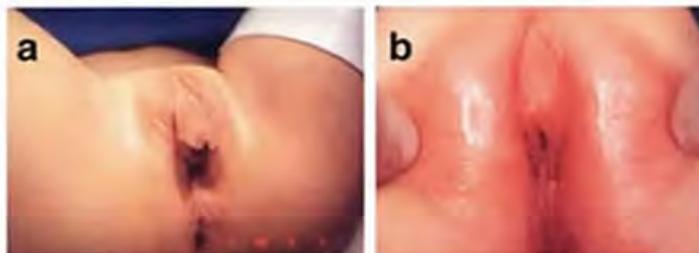
6a-c: Darstellung des Klitorisschaftes (a) sowie der Schwellkörper (b+c).



7a+b: Partielle Resektion der Corpora cavernosa clitoridis.



8a+b: Refixation der Corpora cavernosa clitoridis. "Materialknappheit" bei der Rekonstruktion der Corpora cavernosa clitoridis und der kleinen Labien.



9a+b: Klitorisreduktion und Rekonstruktion des Praeputium clitoridis bei Prader IV.

Source: Finke/Höhne: *Intersexualität bei Kindern*, 2008

Caption 8b: "Material shortage" [of skin] while reconstructing the prepuce clitoridis and the inner labia.



Source: Pierre Mouriouand: "Chirurgie des anomalies du développement sexuel - 2007", at 81: "Labioplastie"

IGM 3 – Sterilising Surgery: Castration / “Gonadectomy” / Hysterectomy

Removal of healthy testicles, ovaries, or ovotestes, and other potentially fertile reproductive organs. “46,XY Complete Androgen Insufficiency Syndrome (CAIS)” is arguably the 3rd most common diagnosis for cosmetic genital surgeries, other diagnoses include “46,XY Partial Androgen Insufficiency Syndrome (PAIS)”, male-assigned persons with “46,XX Congenital Adrenal Hyperplasia (CAH)”, and other male assigned persons, who have their healthy ovaries and/or uteruses removed.

Castrations usually take place under the pretext of an allegedly blanket high risk of cancer, despite that an actual high risk which would justify immediate removal is only present in specific cases (see table below), and the admitted true reason is “better manageability.” Contrary to doctors claims, it is known that the gonads by themselves are usually healthy and “effective” hormone-producing organs, often with “*complete spermatogenesis [...] suitable for cryopreservation.*”

Nonetheless, clinicians still continue to recommend and perform early gonadectomies – despite all the known negative effects of castration, including depression, obesity, serious metabolic and circulatory troubles, osteoporosis, reduction of cognitive abilities, loss of libido. Plus a resulting lifelong dependency on artificial hormones (with adequate hormones often not covered by health insurance, but to be paid by the survivors out of their own purse).

91 M.M. Bailez • Intersex Disorders



Fig. 91.6 An inguinal approach for gonadectomy in a CAIS patient with two palpable gonads

Source: Maria Marcela Bailez: “Intersex Disorders,” in: P. Puri and M. Höllwarth (eds.), *Pediatric Surgery: Diagnosis and Management*, Berlin Heidelberg 2009.

Table 1. Prevalence of type II GCT in various forms of DSD

Risk	Type of DSD	Prevalence %
High	GD in general	12*
	46,XY GD	30
	Frasier syndrome	60
	Denys-Drash syndrome	40
	45,X/46,XY GD	15-40
Intermediate	PAIS	15
	17 β -hydroxysteroid dehydrogenase deficiency	17
Low	CAIS	0.8
	Ovotesticular DSD	2.6
Unknown	5 α -reductase deficiency	?
	Leydig cell hypoplasia	?

GD = Gonadal dysgenesis; PAIS = partial androgen insensitivity syndrome; CAIS = complete androgen insensitivity syndrome.
* Might reach more than 30%, if gonadectomy has not been performed.

Source: J. Pleskacova, R. Hersmus, J. Wolter Oosterhuis, B.A. Setyawati, S.M. Faradz, Martine Cools, Katja P. Wolffenbuttel, J. Lebl, Stenvert L.S. Drop, Leendert H.J. Looijenga: "Tumor risk in disorders of sex development," in: *Sexual Development* 2010 Sep;4(4-5):259-69.

3 months old with scrotal hypospadias and right impalpable gonad

- Uterus and dysplastic gonad removed
- Hypospadias repaired
- Follow-up for surveillance of development testicular and/or renal tumors
- Testosterone required at puberty



Source: J. L. Pippi Salle: "Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)," 2007, at 20.

“Bad results” / “Gonadectomy, Feminising Genitoplasty”



Abb. 2 ▲ a, b Schlechte Korrekturergebnisse nach Feminisierung und c, d nach Hypospadiekorrektur

Caption: 2a,b: “Bad Results of Correction after Feminisation, and”, c,d: “after Hypospadias Repair” – Source: M. Westenfelder: “Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen,” *Der Urologe* 5 / 2011 p. 593–599.

PAIS

- Bilateral gonadectomy
- Skin Biopsy for genetics study of androgen receptors
- Female gender assignment
- Feminizing genitoplasty performed age 6 months









Source: J. L. Pippi Salle: “Decisions and Dilemmas in the Management of Disorders of Sexual [sic!] Development (DSD)”, 2007, at 20.